Glossary of participatory epidemiology terms

PENAPH (Participatory Epidemiology Network for Animal and Public Health)
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Adaptive Methodology for Ecosystem Sustainability and Health (AMESH)

A research and social/behavioural change process that includes multiple stakeholders (both researchers and community members) in framework that explicitly involves both social and ecological systems thinking and design (the ecosystem approach), derived from specific guiding principles, meant to assist research and sustainable development in health to happen in conjunction and cooperatively (Waltner-Toews and Kay 2005).

Case, a

A particular disease, health disorder, or condition under investigation found in an individual or within a population or study group.

Case, b

In medical usage, an individual having a particular disease, disorder, or condition (Adapted from Porta et al. 2008).

Case, index

The first case in a family or other defined group to come to the attention of the investigator (Porta et al. 2008).

Clinical signs

The abnormalities of structure or function observed in the patient by the veterinarian or the client. These are customarily graded according to severity, e.g. severe, moderate, mild, and according to speed of onset and progress, e.g. peracute, acute, subacute, chronic, intermittent (http://www.thefreedictionary.com/clinical+signs).

Community-based participatory research (CBPR)

A research and social change strategy that is focused on gender and social equity and involvement for improving health outcomes (Minkler and Wallerstein 2008).

Contact, direct

A mode of transmission of infection involving fomites or vectors. Vectors may be mechanical (e.g. flies) or biological (when the disease agent undergoes part of its life cycle in the vector species) (Porta et al. 2008).

Contact, indirect

A mode of transmission of infection involving fomites or vectors. Vectors may be mechanical (e.g. flies) or biological (when the disease agent undergoes part of its life cycle in the vector species) (Porta et al. 2008).

Conventional epidemiology

A branch of medical science that deals with the incidence, distribution, and control of disease in a population. Focuses on gathering and analysing quantitative measures and applying that knowledge in interventions to disrupt disease progression in populations (adapted from Merriam-Webster online).

Cross-check (triangulation)

A strategy for data verification, using data from multiple sources to verify results (Coffin 2012) or 'To check (as data or reports) from various angles or sources to determine validity or accuracy' (Merriam-Webster 2013).

Diplomatic biases

For many communities, poverty is the subject of shame, and the needs of the poorest are sometimes glossed over or even concealed, either by the poor themselves or by officials working with them (Mariner and Paskin 2000).

Direct contact

Direct contact transmission takes place when organisms are transmitted directly from the source to the susceptible host without involving an intermediate object; this is also referred to as individual-to-individual transmission (Adapted from NCBI 1996).
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease</td>
<td>The biological dimension of nonhealth, an essentially physiological dysfunction (Porta et al. 2008).</td>
</tr>
<tr>
<td>Disease, preclinical</td>
<td>Disease with no signs or symptoms because these have not yet developed (Porta et al. 2008).</td>
</tr>
<tr>
<td>Disease, subclinical</td>
<td>A condition in which disease is detectable by special tests but does not reveal itself by signs or symptoms (Porta et al. 2008).</td>
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<tr>
<td>Dry season bias</td>
<td>Malnutrition, morbidity and mortality all tend to be highest at the end of the dry season; surveys carried out at other times of the year will miss these phenomena (Mariner and Paskin 2000).</td>
</tr>
<tr>
<td>Ecosystem/ecohealth approaches</td>
<td>‘Ecohealth approaches are systemic, participatory approaches to understanding and promoting human health and wellbeing in the context of complex social and ecological interactions.’ (David Waltner-Toews).</td>
</tr>
<tr>
<td>Endemic</td>
<td>The constant presence of a disease or infectious agent within a given geographic area or population group; may also refer to the usual prevalence of a given disease within such an area or group; used in human, animal, environmental, and ecosystem health (Adapted from Porta et al. 2008).</td>
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<tr>
<td>Epidemic</td>
<td>The occurrence in a community or region of cases of an illness, specific health-related behaviour, or other health-related events clearly in excess of normal expectancy; used in human, animal, environmental, and ecosystem health (Adapted from Porta et al. 2008).</td>
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<tr>
<td>Enzootic</td>
<td>An outbreak (epidemic) of disease in an animal population; often with the implication that it may also affect human populations (Porta et al. 2008).</td>
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<tr>
<td>Epidemiological unit</td>
<td>A group of animals with a defined epidemiological relationship that share approximately the same likelihood of exposure to a pathogen. This may be because they share a common environment (e.g. animals in a pen), or because of common management practices. Usually, this is a herd or a flock. However, an epidemiological unit may also refer to groups such as animals belonging to residents of a village, or animals sharing a communal animal handling facility. The epidemiological relationship may differ from disease to disease, or even strain to strain of the pathogen (OIE 2013).</td>
</tr>
<tr>
<td>Facilitator opinion bias</td>
<td>The facilitator most likely has some preformed opinions about what the situation surrounding the appraisal is, and without great care will allow their own opinions to distort the record of what the participants express (Coffin 2012).</td>
</tr>
<tr>
<td>False negative</td>
<td>Negative test result in an individual who possesses the attribute for which the test is conducted. The labeling of a diseased individual as healthy when screening in the detection of disease (Adapted from Porta et al. 2008).</td>
</tr>
<tr>
<td>False positive</td>
<td>Positive test result in an individual who does not possess the attribute for which the test is conducted. The labeling of a healthy individual as diseased when screening in the detection of disease (Adapted from Porta et al. 2008).</td>
</tr>
<tr>
<td>Focus group</td>
<td>A small number (6–12) people gathered for a group discussion and interview based on their experience or knowledge of a problem or area (Coffin 2012).</td>
</tr>
<tr>
<td>Fomites (singular, fomes)</td>
<td>Articles that convey infection to others because they have been contaminated by pathogenic organisms (Porta et al. 2008).</td>
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<tr>
<td>Gender analysis</td>
<td>A type of socio-economic analysis that uncovers how gender relations affect a development problem. The aim may just be to show that gender relations will probably affect the solution, or to show how they will affect the solution and what could be done. Gender analysis frameworks provide a step-by-step methodology for conducting gender analysis (Wikipedia 2013).</td>
</tr>
<tr>
<td>Household meeting</td>
<td>This generalized term often refers to a meeting of members of a particular household for either informational or data gathering purposes.</td>
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</tbody>
</table>
Incidence: The number of instances of illness commencing, or of individuals falling ill, during a given period in a specified population. More generally, the number of new health-related events in a defined population within a specified period of time. It may be measured as a frequency count, a rate, or a proportion (Adapted from Porta et al. 2008).

Incubation period: The time interval between invasion by an infectious agent and appearance of the first sign or symptom of the disease in question.

In a vector, the period between entry of the infectious agent into the vector and the time at which the vector becomes infective; i.e., transmission of the infectious agent from the vector to a fresh final host is possible (Porta et al. 2008).

Index case: See Case, Index.

Infection: The entry and development or multiplication of an infectious agent in the body of an individual, where it may or may not cause disease (Adapted from Porta et al. 2008).

Infection, preclinical and subclinical: See disease, preclinical and subclinical.

Isolation: 1. In microbiology, the separation of an organism from others, usually by making serial cultures.

2. Separation, for the period of communicability, of infected individuals from others under such conditions so as to prevent or limit the transmission of the infectious agent from those infected to those who are susceptible or who may spread the agent to others. Additional biosecurity measures may also be employed to prevent transmission via indirect contact (Adapted from Porta et al. 2008).

Key informant: Individuals who have had previous experience with the communities under investigation, or are community leaders of one type or another (paraphrase—Mariner and Paskin 2000).

Language bias: The language needed for a semi-structured interview may be poorly translated, and can result in inaccurate results. Note this is actually less common in semi-structured interviews that are well conducted as cross-checking and probing are designed to correct such inaccuracies (Coffin 2012).

Matrix scoring: A visual scoring method which compares at least two indicators, where a two-dimensional grid is used to score items by at least two sets of categories (Jost et al. 2007).

Mode of participation: Similar to the typology of participation, but with six levels of participation instead of seven. (Parkes and Panelli 2001):

1. Co-option;
2. Compliance;
3. Consultation
4. Cooperation
5. Co-learning
6. Collective action

Morbidity: Any departure, subjective or objective, from a state of physiological or psychological wellbeing; it can be measured in terms of three units:

(1) Individuals in a population who were ill,
(2) the illnesses (periods or spells of illness) that these individuals experienced,
(3) the duration (days, weeks, etc.) of these illnesses (Adapted from Porta et al. 2008).

Mortality: The number of deaths occurring in a population.
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**Mutation**
Change in the genetic material not caused by genetic segregation or recombination that is transmitted to daughter cells and to succeeding generations provided that it is not a dominant lethal factor (Porta et al. 2008).

**Outbreak**
And epidemic limited to localized increase in the incidence of a disease, e.g. a single population (Adapted from Porta et al. 2008).

**Pandemic**
An epidemic occurring worldwide or over a very wide area, crossing international boundaries, and usually affecting a large number of individuals (Adapted from Porta et al. 2008).

**Pathogen**
An organism capable of causing disease (literally, causing a pathological process) (Porta et al. 2008).

**Pathogenicity**
The property of an organism that determines the extent to which overt disease is produced in an infected population, or the power of an organism to produce disease (Porta et al. 2008).

**Prevalence**
A measure of disease occurrence: the total number of individuals who have an attribute or disease at a particular time (or period) divided by the population at risk of having the attribute or disease at that time or midway through the period (Porta et al. 2008).

**Participatory action research (PAR)**
A political and social empowerment tool. Focuses on social networks (Neudoerffer et al. 2005).

**Participatory epidemiology (PE)**
Participatory epidemiology is the application of participatory methods to epidemiological research and disease surveillance. It is a proven technique, which overcomes many of the limitations of conventional epidemiological methods, and has been used to solve a number of animal health surveillance and research problems (Jost et al. 2007) or Participatory epidemiology (PE) is based on conventional epidemiological concepts but uses participatory methods to solve epidemiological problems. It is a practical approach to epidemiology that gives stakeholders a greater role in shaping programs (Jost et al. 2007).

**Participatory disease surveillance (PDS)**
The application of PE to disease surveillance. PDS is a method of disease surveillance where participatory appraisal approaches and methods are used to combine local veterinary knowledge with conventional methods to establish the presence or absence of a specific disease in a particular area (Ameri et al. 2009).

**Participatory learning and action (PLA)**
A general term for methods that encourage people, especially poor people, to analyse and solve problems in their own communities. Also the title of an informal journal by the IIED (International Institute for the Environment and Development) (Coffin 2012).

**Participatory mapping**
An exercise where participants collectively draw a map of their area of expertise/community, including details that they and/or the facilitator are concerned with or decide are important (Coffin 2012).

**Participatory rural appraisal (PRA)**
Uses many of the same techniques as RRA, but with the key difference that it is meant to be 'by, for and with' the local people. (Chambers 1994b). Knowledge gained is meant to be owned by local people and shared with outsiders. Outsiders are facilitators but not directors. It is used in a variety of ways that range from fully participatory to mostly extractive (Coffin 2012).

**Participatory urban appraisal (PUA)**
Similar to PRA but with urban populations instead of rural, focuses on finding solutions to problems (Coffin 2012).

**Person bias**
Influential persons interviewed (particularly as key informants) are often either biased against poor people, or ignorant of their needs. The 'rural elite', while not at all representative of the cross-section of farmers, is often the most vociferous at group interviews, and can give the wrong impression. Thus, it is essential to include the rural poor as key informants and ensure they are interviewed in settings where they feel comfortable enough to express their views. In addition, there is a tendency for both interviewers and interviewees to be men; the needs of women, and their contribution to farming, thus remain 'invisible' (Mariner and Paskin 2000).
Politeness bias/ facilitator leading question bias
Participants may choose to tell the facilitator what they believe the facilitator wants to hear, or the facilitator may unintentionally lead participants to respond in certain expected or hoped for responses (Coffin 2012).

Political/powerful opinion bias
There may be a prevailing opinion that ‘everyone’ in the community ascribes to publicly, though they may have privately differing opinions or observations. Similarly, one or more opinion might be the politically savvy thing for participants to express; this can take the shape of currying favour with local political leaders, or in trying to leverage the research to get as much financial or other assistance out of a project as possible (Coffin 2012).

Professional bias
Professional training may in itself be an obstacle, making it difficult for the researcher to understand the linkages in the system they are trying to observe, or leading them only to “see” the richer segment of rural society (Mariner and Paskin 2000).

Project bias
Visitors and researchers are often channeled to areas where projects have been active (there is ‘more worth seeing’ in such places), and most of the work will then concentrate on these places (Mariner and Paskin 2000).

Proportional piling
A semi-quantitative method for determining community priorities, involving the distribution of a counter between different categories. This can be modified to draw out various subtleties in community opinion (Coffin 2012).

Purposive sample (risk-based sample)
Sampling with a purpose or sampling based on a characteristic (or risk), aims to capture a section of the population that is most likely to exhibit a trait (or problem). This type of sampling is often used in sociological studies (Trochim 2006).

Random sample
A sample in which every element in the population has an equal chance of being selected (thefreedictionary.com).

Rapid rural appraisal (RRA)
A mostly extractive/elicitive technique used to get useful, honest, and representative social information (for development) in a short amount of time. Usually yields qualitative data, but occasionally quantitative data also. Makes use of the concepts of optimal ignorance, quickly established rapport, and triangulation. Knowledge is often owned by the outsider and sometimes shared with the local people (Chambers 1994a).

Recall bias
Memory does not always accurately represent true events, and those studies that rely upon memories from past years are vulnerable to this bias (Coffin 2012).

Risk
The probability that an event will occur, e.g. that an individual will become ill or die within a stated period of time or by a certain age (Porta et al. 2008).

Risk-based sample
See purposive sample.

Risk factor (indicator)
1. An aspect of individual behaviour or lifestyle, an environmental exposure, or an inborn or inherited characteristic that, on the basis of scientific evidence, is known to be associated with meaningful health-related condition(s).

2. An attribute or exposure that is associated with an increased probability of a specified outcome, such as the occurrence of a disease. Not necessarily a causal factor: it may be a risk marker.

3. A determinant that can be modified by intervention, thereby reducing the probability of occurrences of disease or other outcomes (modifiable risk factor) (Adapted from Porta et al. 2008).

Sampling bias
If only a small number of sampling locations are used, they may not accurately represent an entire region (Coffin 2012).

Seasonal calendar
A visualization technique that attempts to map events that occur seasonally, usually looking for correlations between events of interest (such as disease) and climatic, social, or other seasonal changes (Coffin 2012).
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Semi-structured interview
An interview, with either individuals or groups, that has been outlined prior to enactment but is specifically designed for the flexibility to pursue topics of interest or need for clarification as and if they arise (Coffin 2012).

Sensitivity
The probability that a diseased individual in the population tested will be identified as diseased by the test (true-positive probability, true-positive rate) (Adapted from Porta et al. 2008).

Sentinel health event
A condition that can be used to assess the stability of change in health levels of a population (Porta et al. 2008).

Serology
A branch of science dealing with the measurement and characterization of antibodies and other immunological substances in body fluids, particularly serum (Porta et al. 2008).

Seronegative
An individual whose serological results suggest that they have not experienced a specific infection at some time in the past.

Seropositive
An individual whose serological results suggest that they have experienced a specific infection at some time in the past.

Serotype
The type of a micro-organism determined by its constituent antigens based on one of several different antibody–antigen reactions, or a taxonomic subdivision based thereon (Saunders Comprehensive Veterinary Dictionary 2007; http://medical-dictionary.thefreedictionary.com/serotype).

Social network analysis (SNA)
The methodical analysis of social networks. Social network analysis views social relationships in terms of network theory, consisting of nodes (representing individual actors within the network) and ties (which represent relationships between the individuals, such as friendship, kinship, organizational position, sexual relationships etc.). These networks are often depicted in a social network diagram, where nodes are represented as points and ties are represented as lines (Wikipedia 2013).

Socio-economic analysis
A socio-economic impact assessment examines how a proposed development will change the lives of current and future residents of a community. (http://www.lic.wisc.edu/shapingdane/facilitation/all_resources/impacts/analysis_socio.htm), or ‘To assess whether the socio-economic benefits outweigh the risks to human health and the environment’ (Wikipedia).

Spatial biases
(roads bias/travel convenience bias)
Occur when PA facilitators fail to take into account spatially determined confounding factors, for example, by only dealing with villages or communities along convenient or accessible roads or flight paths where circumstances are most likely different than away from easy travel routes (Coffin 2012).

Specificity
The probability that an individual without the disease (noncase) will be correctly identified as non-diseased by the test (true-negative probability) (Adapted from Porta et al. 2008).

Sporadic
Occurring irregularly, haphazardly, from time to time, and generally infrequently (e.g. cases of certain infectious diseases) (Porta et al. 2008).

Structured interview
Structured interviews involve questions, which are set out and followed thoroughly. Each candidate is presented with the same questions and this ensures that each respondent has had the opportunity to respond to each question (http://www.psyasia.com/supportsuite/index.php?_m=knowledgebase&_a=viewarticle&kbarticleid=191!ixzz2KqHV67Zl).

Surveillance
Systematic and continuous collection, analysis, and interpretation of data, closely integrated with the timely and coherent dissemination of the results and assessment to those who have the right (or the need) to know so that action can be taken (Porta et al. 2008).
Susceptibility

1. Vulnerability; lack of resistance to disease; the dynamic state of being more likely or liable to be harmed by a health determinant.

2. The condition or status of having one or two interacting causes already and therefore being susceptible to the effect of the other.

3. A process occurring over time during which host factors (both inherited and learned or otherwise acquired and embodied) increase the likelihood that an exposure will produce disease. Susceptibility to positive influences and beneficial outcomes also exists (Porta et al. 2008).

Sustainable activities

A systems-oriented approach to understanding complex ecological, social, and environmental interactions in a given context (Adapted from Pretty 1994).

Symptom

Any subjective evidence of disease or of a patient’s condition, i.e. such evidence as perceived by the patient; a change in a patient’s condition indicative of some bodily or mental state (http://medical-dictionary.thefreedictionary.com/symptom).

Timeline

A visualization activity that attempts to clarify when historical events have taken place, linking events that are important ‘timekeepers’ for activity participants with a dating method that can be more universally understood (Coffin 2012).

Tracing

To ascertain the successive stages in the development or progress of a disease (Adapted from The Free Dictionary 2013).

Transect

A path along which one counts and records occurrences of the phenomena of study (e.g. plants) (Wikipedia 2013).

Transect walk

Facilitators and participants (in a small, 2–4 persons, group) walk together along a specified route, or transect, through the community observing and discussing resources, features, landscape, and main land use as it pertains to problems or questions being addressed (Adapted from World Bank).

Transmission

Any mechanism by which an infectious agent is spread from a source or reservoir to another individual. Can be indirect or direct, as in direct or indirect contact.

Triangulation

(See cross-checking).

Triple task

A process for evaluating the health of the group dynamics that emerges during focus group sessions. The three tasks operate in parallel at the same time.

Task 1: first ‘scoping’ works to draw participants into a group and agree on major task and issues, then visions of change are used to come up with an agreement on what needs to be done; planning for the desired change is then initiated in practical steps.

Task 2: is a review of the group dynamic from the ‘outside in’ (conducted by someone outside the process) following methods of socio-analysis such as the BECM method used in Open University.

Task 3: is an ‘inside out’ evaluation of the group dynamic using a contrasting socio-analysis technique such as Symlog (www.symlog.com, Bell et al. 2012) or the Myers Briggs approach (Adapted from: Bell et al. 2012).
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**Typology of participation (Pretty 1994)**

Inclusive list of stages, or types, of participation that a project, intervention, or process can achieve. Seven levels have been described.

1. **Passive participation**—People participate by being told what is going to happen or has already happened. It is a unilateral announcement by an administration or project management without any listening to people’s responses. The information being shared belongs only to external professionals.

2. **Participation in information giving**—People participate by answering questions posed by extractive researchers using questionnaire surveys or similar approaches. People do not have the opportunity to influence proceedings, as the findings of the research are neither shared nor checked for accuracy.

3. **Participation by consultation**—People participate by being consulted, and external agents listen to views. These external agents define both problems and solutions, and may modify these in the light of people’s responses. Such a consultative process does not concede any share in decision-making, and professionals are under no obligation to take on board people’s views.

4. **Participation for material incentives**—People participate by providing resources, for example labour; in return for food, cash or other material incentives. Much on-farm research falls in this category, as farmers provide the fields but are not involved in the experimentation or the process of learning. It is very common to see this called participation, yet people have no stake in prolonging activities when the incentives end.

5. **Functional participation**—People participate by forming groups to meet predetermined objectives related to the project, which can involve the development of promotion of externally initiated social organization. Such involvement does not tend to be at early stages of project cycles or planning, but rather after major decisions have been made. These institutions tend to be dependent on external initiators and facilitators, but may become self-dependent.

6. **Interactive participation**—People participate in joint analysis, which leads to action plans and the formation of new local institutions or the strengthening of existing ones. It tends to involve interdisciplinary methodologies that seek multiple perspectives and make of systematic and structured learning processes. These groups take control over local decisions, and so people have a stake in maintaining structures or practices.

7. **Self-mobilization**—People participate by taking initiatives independent of external institutions to change systems. Such self-initiated mobilization and collective action may or may not challenge existing inequitable distributions of wealth and power.

**Vector**

An insect or any living carrier that transports an infectious agent from an infected individual or its wastes to a susceptible individual or its food or immediate surroundings. The infectious agent may or may not pass through a developmental cycle within the vector (Porta et al. 2008).

**Virulence**

The degree of pathogenicity; the disease-evoking power of a microorganism in a given host. Numerically expressed at the ratio of the number of cases of over infection to the total number infected as determined by immunoassay. When death is the only criterion of severity, this is the case-fatality rate (Porta et al. 2008).

**Zoonosis**

An infection or infectious disease transmissible under natural condition between vertebrate animals and humans. May be enzootic or epizootic (Adapted from Porta et al. 2008).
References


Coffin, J.L. 2012. Applying participatory approaches in conservation medicine. (Unpublished MSc thesis). Tufts Cummings School of Veterinary Medicine, Grafton, Massachusetts, USA.


http://www.thefreedictionary.com/clinical+signs


Merriam-Webster online 2013.


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